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LEPROSY

Dr. Shaik Khader NOORDEEN, Director of the World Health Organization's Action Programme for the Elimination of Leprosy, discusses this dreaded disease and its impact on individuals and societies. Leprosy is caused by a bacillus which reproduces very slowly and affects the skin, nerves and limbs. It is difficult to catch; infection requires frequent and long-term exposure. In the past, sufferers were forced to live in isolation and were shunned by their own communities. The first breakthrough in treating leprosy came in the 1940s with the development of the drug dapsone. And with current multi-drug therapy (MDT) leprosy can be cured for much less than it costs to treat AIDS. Although leprosy has been eliminated in Europe, it remains a public health problem in 60 countries or areas. Dr. Noordeen says WHO supplies the drugs needed to treat about 1 million patients every year in more than 25 countries.

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ANNOUNCER: From United Nations Headquarters in New York, this is **World Chronicle**, an unedited interview programme about major global issues. Here now to introduce our guest is the host of today's **World Chronicle**.

LITTLEJOHNS: I'm Michael Littlejohns, and this is **World Chronicle**.

Despite advances in medicine and medical technology, a number of devastating diseases still exist in many parts of the world and adversely affect the lives of millions of people. One of the most dreaded is leprosy. Today, there are more than one million cases of leprosy in about 60 endemic countries. And every year more than half a million new cases are detected. How are people infected with leprosy? And is it possible to eradicate this disease once and for all?

Our guest today is an expert in leprosy control. He is Dr. Shaik Khader Noordeen, Director of the World Health Organization's Action Programme for the Elimination of Leprosy.

Joining me to talk with Dr. Noordeen are Thalif Deen of Inter Press Service and Tuyet Nguyen of DPA, the German Press Agency. Dr. Noordeen, welcome to World Chronicle.

NORDEEN: Thank you.

LITTLEJOHNS: Dr. Noordeen you've mentioned before we went on the air, that you have been involved with this problem for about forty years, yet you have not contracted the disease. Although it is very devastating as we said in the introduction, and we have all seen pictures of the terrible effects of it, but it is not easy to get, I gather?

NORDEEN: Well, certainly leprosy is not an easy disease to catch, it is an infectious disease but a very feebly infectious disease. Normally, leprosy is transmitted within very poor conditions in households where leprosy...

LITTLEJOHNS: Poor sanitation.

NORDEEN: It's a question of proximity between an individual who is exposed to the disease and a leprosy patient, and if these people live together, for months and years and a very poor hygienic condition, then the possibility that leprosy germ would get out of the person having leprosy and be inhaled through the respiratory root, by a person who is exposed to the disease, is significant, but quite low compared with many other diseases. If I had to put it in quantitative terms, if and individual lives with the leprosy patient within the household, the chances that this individual would get leprosy for a period of one year of exposure is between one and two per cent. So while it is not nil, it is still very low.

NGUYEN: What causes leprosy doctor?

NORDEEN: Leprosy is caused by a germ. We call it a micro bacterium leprae.

It's a germ which is somewhat related to the germ that causes tuberculosis, but these two are different in many other ways. And, the germ occurs, or is formed, in the lesions of individuals having the more severe form of leprosy and this individual can through the respiratory root, transmit the germ to a person exposed to the disease.

NGUYEN: So it happens mostly in tropical countries where hygienic and sanitations regulations are not that strict, as in western countries. Is that true?

NORDEEN: It's partly true. Leprosy is largely a disease of the third world. For many reasons, leprosy is a disease which is identified with a lot of underdevelopment. I won't say that the disease is essentially a disease that occurs in warm climate. Because only a hundred ago, leprosy was not an uncommon disease in Europe, or even in some parts of the United States, irrespective of the weather conditions then being the same as now. At the same, time today most of the countries in the third world have leprosy.

LITTLEJOHNS: So how is it eliminated in Europe without the benefit of these modern drugs, which apparently have had a tremendous effect in.. if not eliminating the scare, at least controlling it to a great extent.

NORDEEN: Nobody really knows how leprosy was eliminated from Europe. There are many theories. One of them was that there was practice of strict isolation of patients in hospitals, and so..

LITTLEJOHNS: That rather contradicts what you said earlier that it is a feeble infection.

NORDEEN: It's true. But at the same time. This one person risk, this two person risk I mentioned is not a zero risk, but if there is going to be a community of one thousand people exposed to leprosy, then a certain number will develop. And because leprosy is a chronic disease, the chances of contact between an exposed person and a disease person is very long. So it increases the risk in total.

DEEN: From the numbers I have seen, WHO has been very successful in eradicating the disease gradually. But there is also a social stigma attached to this disease. How do you cope with this problem, particularly in third world countries?

NORDEEN: This is a major problem. Not only is it a big suffering and a human issue for the patient suffering from leprosy, even after they are cured if they have severe deformities, there is also a problem of making the patients to come forward for treatment to the health centres and take advantage of the treatment that is being offered to these people. So the only way we can address this problem is to get the message across through media approaches and other information campaigns to tell people that leprosy is like any other disease, it can be cured today, there is not need to fear leprosy.

DEEN: How successful are you in....

NORDEEN: We have been tremendously successful. In the early days, about twenty years ago, the leprosy treatment was less successful, no matter how much information you can read to the people, people are not convinced about arguments that leprosy is like any other disease. But today, people see leprosy patients being cured within their communities, there is no other message that is better than the demonstration message.

DEEN: What do you think the [?] are used to shun someone for moral reasons?

NORDEEN: The word leper is used in a different sense of referring to a person with moral issues. But to call a leprosy patient a leper is treating that individual in a very inhuman way. You never call an individual after the disease he has. So we would like to strongly advocate, particulary the media, never to use the word leper to refer to your fellow human being who is unfortunately afflicted by a disease, which is like any other disease.

NGUYEN: Only a social stigma, how do you compare that with AIDS victims, for example?

NORDEEN: It's extremely interesting, the kind of social stigma against AIDS which I read now, brings back all the memories we have of how leprosy has been handled in the past and to some extent, even now. In terms of the stigma, a lot of it relates to the fear of the disease. And very often, the fear is translated into treating the individual suffering from the disease as someone who is an outcast. And not deal with the person or treat the person as a fellow human being.

NGUYEN: But it is easier to get AIDS these days than it is to get leprosy?

NORDEEN: You can say that. Although the mode of transmission or the way people get the two diseases are totally different.

DEEN: You also had this concept of leper colonies right?

NORDEEN: Exactly. In the world, people have and are afraid of leprosy. The only way they can deal with them is, kick them out of the community.

LITTLEJOHNS: But this is was how the problem was solved in Europe, apparently.

NORDEEN: O.K., it's inhuman, but it partly contributes, I must admit that. But it's very inhuman for many reasons because while trying to solve a problem which is of health interest, you are creating a huge social problem; in terms of people being dislocated from the families and certainly today with the effective treatment, there is no argument of in favor of isolating patients or sending them out. You can isolate them chemically by treating them.

LITTLEJOHNS: Are there so called – leper colonies in developing now?

NORDEEN: Well, they still exist. For two reasons. One, that some of these patients need special attention because there are complications... it is more like a hospital. But more than that, in the past, leprosy patients who have been thrown out of the communities because they had the disease and they had deformities they have no place else to go. So a

few institutions or sometimes even self direct colonies had developed in some countries, so these patients live in these colonies at present, looked after by some agency or the other and in a sense, it is acting more as a rehabilitation or a center for disabled people so that they can be looked after better. But even among the disabled persons, viewed like from WHO to advocate, if a leprosy patient is disabled, this person should be rehabilitated within the family and within the community. And they should develop a methods to cope with that.

NGUYEN: In the AIDS epidemic, there is an educational program, you know, tv ads, newspapers and so on. Asking people not to discriminate the victims, you don't see that with the leprosy?

NORDEEN: You don't see that in the countries where AIDS media is very strong, like in North America or Europe. But in third world countries, we are trying to convey the message to the communities, that leprosy patients should not be discriminated. And to me, more than as against AIDS, we are telling people you see, we can cure leprosy, you see these people who are who have a disability, they are not a danger to the community. So accept them as normal [?]. So through the process of demonstration and the process of as you said, information not as high scale or as high profile, as in AIDs, we are sending the message across. I won't say that we are one hundred per cent successful, we are only partly successful.

NGUYEN: Can you talk about cost also. It is very costly to treat an AIDs victim than a leprosy patient. How much more expensive it is?

NORDEEN: How much less expensive is leprosy to treat. Leprosy patients, we have largely two kinds of disease. One, a milder form of the disease which we technically call paucibacillary leprosy, and our more severe form of the disease, which we technically call multibacillary leprosy. For the milder form of leprosy, the cost of treatment, actually the treatment has to begun for only six months. is three dollars.

NGUYEN: Per day?

NORDEEN: No! for the whole treatment.

NGUYEN: For the whole treatment.

NORDEEN: And for the...

LITTLEJOHNS: Which covers for how long a period?

NGUYEN: Six months.

LITTLEJOHNS: Really.

NORDEEN: And for the more severe form, the treatment is only for twelve months and the cost is about twenty-five dollars. So in terms of cost of drugs, is quite low per patient. But if you look at countries who share a large number of patients, which are difficult

in importing this kind of drugs into their countries, their difficulties in finding the drugs to treat the patients.

DEEN: How much does WHO spend?

NORDEEN: Let me explain. In terms of addressing this problem of getting drugs to the patient who need them, WHO has a very special initiative for the last three years or so, in which we provide all the drugs the patients need in the countries for treatment of leprosy. Who does WHO make it? Because WHO had been able to negotiate and obtain a large donation for this specific purpose of buying drugs and distributing to the countries, so the patients can get the drugs. These donations has been provided to us by a foundation in Japan which is called, Nippon Foundation. It has been extremely valuable contribution in seeing. So today, we have about nine hundred thousand leprosy patients, registered for treatment in a very large number of countries.

LITTLEJOHNS: Sixty, I think we said in the introduction.

NORDEEN: Sixty countries have significant problems, of having leprosy more than one in ten thousand per relence. That is just a markup. But other countries in smaller numbers and smaller problems of patients. In any case, we have world-wide, about nine hundred thousand patients identified by health services as participations in reoccurring treatment. Ninety seven per cent of these patients are today getting multi drug therapy of drugs free of cost.

LITTLEJOHNS: Dr. Noordeen, because of this social stigma, to which we referred, and you mentioned nine hundred thousand cases, what about the cases that are not reported, do you have an estimate of those?

NORDEEN: We have an estimate. In fact leprosy has been reduced for the last fifteen years by about eighty five percent. We use to have a estimated ten to twelve million patients even as recently as 1985. Today, we have an estimated leprosy burden a little over one million. Now, because we have been able to cure a very large number of patients, to date some eight and a half million patients are being cured through multi drug therapy. But the remaining challenge is very important for us and very difficult. The first part of eighty five per cent is regularly easy compared to the remaining difficult part and it is these numbers which we estimate now – we need to reach another two million leprosy patients, between now and the year 2000 which is our target date, for eliminating leprosy as a public problem. But we cannot use the world methods to reach the remaining patients because these are the difficult situations and the difficult patients.

LITTLEJOHNS: This is **World Chronicle** our guest is Dr. Shaik Khader Noordeen, Director of the World Health Organizations Action Programme for the Elimination of Leprosy.

Doctor Noordeen, the problem of refugees is a very serious one in many countries and displaced persons. When there are so many people thrown together in pretty terrible conditions in many camps, is leprosy becoming a problem there too?

NORDEEN: We suspect leprosy is an important problem among the refugees and we are trying to obtain information from refugee camps. The preliminary information we get is even within the refugee camps, leprosy patients are discriminated. And not allowed to stay. The second situation is, while we all talk about refugees in camps, there are large numbers of refugees outside camps.

LITTLEJOHNS: Just wandering around.

NORDEEN: Yes, and among them are significant numbers of leprosy patients, and obtaining information on those people is very difficult because they would not admit that they are refugees. Because they are already tried to assimilate to the surrounding community. But we are helping these countries which have within their population, a proportion of refugees who are treated as normal population of that country. And we are trying to help these countries treat these patients. But unfortunately, we are not able to get precise information of these leprosy patients among refugees outside their camps and within the camps at least a preliminary information suggest – that leprosy are encouraged to stay.

NGUYEN: I want to ask you something in Vietnam, they believed that if you live near a gold mine and bring the spring or the water that comes through that mine, it can cure leprosy. I wonder how correct is that belief and why is gold can help?

NORDEEN: Certainly, leprosy cannot be cured by any amount of gold, whether it is through the water or some other means. But many of these belief exist in leprosy because as you look at a primitive community or a simple community, you look at leprosy as a disease which really cripples people for a period of years. It is said, leprosy is dreaded not because it kills, but because it leaves one alive. O.K., so with this background, people have to find some explanation why they got it. In Vietnam or China they would say, if there is a snake bite you'll get leprosy, or if you do this or in some other countries, they will say it is your karma of the sins you did in the past life, then you'll get leprosy. So you got a whole lot of explanations for leprosy because people could not understand why this unfortunate people got the disease. Then when it comes to a cure, they also look at very exotic ways of curing the disease. Not by herbs or medicine but they think it must be gold because gold is already expensive or it must be some special spell from some person that should cure leprosy. So all of these beliefs exist. But these are changing.

DEEN: Doctor, I note in reading the other day, that six hundred and fifty thousand cases, registered cases of leprosy patients in India alone, would this be the largest single number of any country?

NORDEEN: Well, exactly. India contributes to about sixty five per cent of all leprosy patients in the world today. But the six hundred and fifty thousand patients is a big share. But if you look at the sexes India has achieved in leprosy, they use to have four million patients fifteen years ago.

DEEN: Leprosy patients?

NORDEEN: Exactly, and they have reduced it to six hundred and fifty thousand. I looks big, but they have done some job, but they have to reduce it further and they are working on it.

DEEN: To what extent is WHO responsible for the reduction?

NORDEEN: I think WHO works closely with its member countries, it works very closely with many bilateral agencies, it works very closely with NGOs. WHO has pushed good technologies for these organizations [?].....technology and is promoting the technology. This helping countries to get this technology across and it is developing strategies so that they can implement these technologies in the most appropriate way. And lastly, they are giving them a target of eliminating of leprosy by year 2000 reducing the prevalence below one in ten thousand, and we are monitoring it very closely. With all these inputs, and with very close collaboration, WHO has been in a position to address this problem through the countries in a serious way.

DEEN: And your bigger singular achievement has been the eradication of smallpox.

NORDEEN: Exactly.

DEEN: Do you think you'll have the same degree of success with leprosy?

NORDEEN: It's difficult to compare smallpox with leprosy. Smallpox eradication was extremely important until you reach the last case of smallpox. Because if you leave one case of smallpox behind, it will lead to an explosion of an outbreak and then it will come back again. With leprosy, the target is eliminating leprosy as a public heath problem, reducing it to very insignificant levels so that over a period of time, the disease will disappear due to efforts in how you treat patients, etc. The few cases you leave behind, by the year 2000, are not likely to be a source a new explosion. So leprosy from that point of view, as I said its a very feeble infectious disease, its a less efficient disease, unlike some of the acute infectious diseases like smallpox. So in one way, leprosy elimination will ultimately lead to total eradication over a period of time but it is not exactly the same as in smallpox.

LITTLEJOHNS: Doctor Noordeen, to get away from leprosy for a minute, could you tell us as a senior official of WHO, what other diseases maybe on the line for eradication.

NORDEEN: The number of diseases that are being addressed in this case, you must have heard about the polio eradication..

LITTLEJOHNS: Yes.

NORDEEN: Which is going in big stream in eradication and then there is measles eradication attempts, attempts to eliminate neonatal tetanus, there are attempts to eradicate

LITTLEJOHNS: I'm sorry, what was that again.. neonatal what?

NORDEEN: Tetanus.

LITTLEJOHNS: O.k.

NORDEEN: There are attempts to eradicate diseases like guinevant, and there are attempts to eradicate a disease called chagas disease, which is common in South America. So many of these diseases which have good technologies and good potential, provided we put sufficient intense effort are being targeted. And in the case of other diseases, at present, are mainly to control the diseases.

LITTLEJOHNS: And are they targeted on the basis of fairly low cost drugs, as you mentioned in the case of leprosy?

NORDEEN: Firstly, whatever technology that is employed for elimination of eradication has to be cost effective, otherwise, we cannot reach the large numbers that we have to reach, so that is an important point. And second, the technology must be sufficiently effective and there must be good political will and donor support to address these problems. So, looking at opportunities WHO is aiming at diseases which are targets, and they are working toward them.

NGUYEN: Doctor Noorden, there are now sixty epidemic countries. How many were there – before – let's say ten years ago, or twenty years ago? Was there a much larger amount and number of countries?

NORDEEN: If you look at the definition of an endemic country as a country which with the prevalence more than once case per ten thousand population, twelve years ago, we had one hundred and twenty-two countries. Today we have less than sixty. And we hope to reach and reduce this figure further to close to zero by the year 2000.

NGUYEN: Is there any country where the leprosy is completely eradicated?

NORDEEN: I would not say eradicated, but in terms of achieving this goal of elimination, as I said, from one twenty it has become less than sixty, and in many countries which have done this reduction in a dramatic way – including – many countries in Africa and the condition of extreme difficulties.

DEEN: Doctor Nordeen, most UN agencies are facing problems of resources. Does WHO also have problems of resources?

NORDEEN: Most certainly it does. But in the case of our leprosy program, we have been fortunate in being able to convince people about what we can achieve in leprosy and thanks to the promotion efforts of WHO, they are able to receive extrabudgetary funds

outside the regular budget, support for leprosy program. And in fact, a large number of programs in WHO depend to a considerable extent on this kind of voluntary contributions based on performance. And there is one that is enabling us go ahead further.

DEEN: Who is it that decides on the priorities? Is it the World Health Assembly? Or the WHO?

NORDEEN: No. The WHO is essentially guided by its governing bodies and in the World Health Assembly and the Executive Board. And it is these bodies that lay down the broad targets.

LITTLEJOHNS: Doctor Noordeen, you told us that the cost of curing leprosy is relatively low and can be done in six or twelve months, depending one the person who is affected, the sufferer. But surely rehabilitation for people who had limbs badly damaged deformed, lost limbs, must be enormously expensive.

NORDEEN: Oh its'....

LITTLEJOHNS: And how does WHO handling that?

NORDEEN: At present, our priority is to get every patient and their treatment. So that, we don't add to the burden to disabled persons any more. Our instrument is, by promoting and implementing multidirect therapy for the last ten, fifteen years, they prevented two million people from becoming disabled. Of course, we don't see these two million people because they are the people who otherwise got the disability. So this is an indirect benefit, but a very important benefit from identifying patients early and treating them promptly. But in addition, we think there are about two million leprosy patients in the world today, who, in spite of having been cured, have residual deformities, who need rehabilitation and other care. Now our priority for the moment is not on this rehabilitation because its a highly expensive operation. And we depend for this essentially on Non-Governmental organizations. They are able to relate to this problem, better than global organizations because WHO talks to governments on priority for rehabilitation and putting this under rehabilitation, they have difficulties in dealing with these issues not only for leprosy but polio, or victims or other injury victims and other, and all who need rehabilitation. The current operation of WHO is to take all these people who are disabled due to various reasons and try to use community based approach. In trying to use simple technologies, simple methods so that the patient remains within the communities and get a degree of rehabilitation. I must admit, this is not highly effective as in the case of a more focused approach. But this is being done now.

LITTLEJOHNS: Doctor Noordeen, that's all the time we have. Thank you for being with us on this edition of **World Chronicle**. Our guest has been Dr. Shaik Khader Noordeen Director of the World Health Organization Action Programme for the Elimination of Leprosy.

He was interviewed by Thalif Deen of *Inter Press Service* and Tuyet Nguyen of DPA the *German Press Agency*.

I'm Michael Littlejohns, thank you for joining us. We invite you to be with us for the next edition of **World Chronicle**.